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The treatment journey of a patient with multidrug-resistant tuberculosis in South Africa: is it patient-centred?

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Summary

To improve the treatment of patients co-infected with multidrug-resistant tuberculosis (MDR-TB) and the human immunodeficiency virus, we measured the relationship between treatment outcomes and hospital performance at four decentralised MDR-TB sites in South Africa. We describe hospital performance from the patient's perspective by the use of a graphic that visually represents a patient's treatment journey. The graphic was used to report study findings to study site

Keywords

health systems; high burden of TB and HIV

Situation/Setting

KwaZulu-Natal is the centre of the global TB and HIV epidemics – and has one of the largest drug-resistant tuberculosis epidemics in the world.^{1,2} Most patients (75%) with multidrug-resistant tuberculosis (MDR-TB) are co-infected with HIV, requiring the provision of protracted care from health services.³ To provide treatment for patients closer

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Contributors

Conceived and designed the study: ML, NP, AV, JB, KW

Performed the study: ML

Analysed the data: ML, NP, AV, JB, KW

Wrote the paper: ML, NP, AV, JB, KW

Ethics approval

The study protocol was approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref: BF052/09).

Conflicts of interest

We declare that we have no conflicts of interest.

to their homes, a decentralized model of treatment was initiated in 2009 at four rural hospitals. In accordance with the South African guidelines patients were treated with a standardized MDR-TB regimen. During the initial intensive phase of treatment (usually 4–6 months), patients were started on a six-drug regimen of kanamycin (Km), pyrazinamide (Z), ethambutol (E), ethionamide (Eto), ofloxacin (Ofx), and cycloserine (Cs). This was proceeded by an additional 18 months of oral treatment with five drugs (Z, E, Eto, Ofx and Cs). All patients co-infected with HIV received standard cotrimoxazole prophylaxis and were eligible to receive ART in accordance with the South African Antiretroviral Treatment guidelines consisting of a once-daily ART regimen of efavirenz and twice-daily lamivudine and stavudine (d4T);⁴ from April 2010 tenofovir replaced d4T.⁵

We conducted a prospective cohort study to determine the effectiveness of decentralised model of care for MDR-TB patients and a health systems study to determine the impact of health systems factors on treatment outcomes. Details of the decentralised model of care and study findings have been reported elsewhere.^{6–9} Treatment outcomes as defined by the WHO were used to measure patient response to treatment.^{10,11} Cure was defined as completion of treatment with consistently negative cultures in the final year of treatment and reported in 51% of the patients enrolled.

To illustrate the most common health systems factors which were obstacles to optimal care we created a graphic which visually represents a patient's treatment journey and used this to convey study findings to district and decentralised MDR-TB hospital managers. Here, we describe the graphic which highlights an individual patient's journey as an example of the challenges faced by many MDR-TB patients.

Aspect of interest

The treatment journey described is that of a real patient, and is typical of the treatment journeys of many other patients - as determined by an audit of 163 (10.5%) medical records. So, for example, not only were this patient's clinical notes missing (as shown in the figure), but of the 1549 patients reviewed, notes of 226 (15%) patients were lost. The 35 year old woman, on whom the treatment journey is based, was a single parent with three young children, living in a rural area 35kms from the decentralised MDR-TB hospital. She was co-infected with MDR-TB and HIV and started treatment in early 2009. We selected this patient as her treatment was compromised by the most common health systems obstacles we observed, and furthermore, she was representative of our study sample - for the whole study cohort, the median age was 35 years [IQR 27–43], 52% were female and 75% co-infected with MDR-TB and HIV. She experienced many obstacles to optimal therapy, some located in the health system, whilst others were related to her own socio-economic status.

The figure depicts the patient's receipt of MDR-TB and HIV treatment over the 24 month treatment course, as represented by the X-axis. The coloured bars represent the extent of the treatment she received each month and have been coloured in red, orange and green to represent the colours of a traffic light:

Red represents months in which the patient received no treatment.

Orange represents months in which the patient received incomplete treatment - she received some but not all the treatment she required according to the national guidelines.

Green represents months in which the patient received all her treatment.

The Y-axis is divided into seven blocks. The block at the bottom represents anti-retroviral therapy (ART) and the remaining six blocks represent the six MDR-TB drugs. If treatment was compromised, one block is coloured red representing missed treatment, and the rest of the column is coloured orange representing incomplete treatment. The boxes above the graph describe the obstacles to optimal treatment. Health system factors are represented by pink boxes whilst green boxes represent patient-related factors.

Current South African guidelines recommend initiating ART within a month of MDR-TB treatment initiation; however, when the patient started treatment in 2009, TB and HIV services were poorly integrated and she only started ART seven months after MDR-TB treatment initiation. Therefore in the figure for the first seven months of treatment, one block is red to represent the missing ART and the rest of the columns are orange representing incomplete treatment - no ART.

In the seventh month of treatment, the patient came to the hospital for her scheduled outpatient appointment, but the hospital internet was not working. As the laboratory website was inaccessible the patient's most recent sputum culture results were unavailable. Consequently, the standardised regimen was issued, despite the doctor not knowing whether the patient was responding to treatment or not.

In the ninth and tenth month the public workers' strike affected all health facilities in KwaZulu-Natal and the patient perceiving she would not be attended to, did not go to the facility, as represented by the red columns in the ninth and tenth months of treatment.

During months 12 and 23 of treatment, there were stock-outs of different drugs – ofloxacin and ethambutol respectively. On both occasions four drugs were dispensed for the month, instead of the five-drug regimen recommended in the MDR-TB treatment guidelines for the continuation phase of MDR-TB therapy.

In the 15th and 21st months the patient was unable to come for treatment for patient-related socio-economic factors as represented by boxes shaded in green above the graph. In the 15th month she was unable to come to the hospital as an environmental problem -heavy rain - made the dirt road closest to her home impassable, and it was too far for her to walk to the hospital. In the 21st month she had no money for transport.

Lastly, in month 18, when she arrived for her appointment, her clinical notes could not be found, and the standardised regimen was issued, although, due to visual problems she had developed, the standardised regimen had been adapted for her and ethambutol discontinued.

In summary, for more than half (58%) of this patient's 24-month treatment journey, she received inadequate treatment, despite adhering to her visit schedule most of the time. The patient received full treatment for 10 months or 42% of the treatment time and incomplete

treatment for a similar length of time. She received no treatment for four months (16% of the treatment time). In spite of this, due to her perseverance through the 24 month treatment period, she was cured.

Discussion

Both patient and health system related factors resulted in sub-optimal treatment, but health systems factors were responsible for most of the obstacles encountered during the patient's treatment journey. Different components of the health system, including pharmaceutical services, laboratory services, the monitoring and evaluation system, provider performance (poor implementation of treatment guidelines), and inadequate integration of TB and HIV services all contributed to this patient receiving sub-optimal treatment for more than half her treatment journey.

The problems illustrated by the patient's treatment journey are typical of those experienced in many national TB and drug-resistant TB programmes. Although individually each obstacle to optimal care is small, the combination of the different obstacles becomes exponential and results in the delivery of incomplete and inadequate treatment, poorly performing national TB and drug-resistant TB control programmes as well as increased drug resistance. Other studies have documented increased chances of unsuccessful treatment outcomes when health systems are dysfunctional.^{12–16} Fragmentation of care, irregular drug supplies, inappropriate regimens resulting from doctors not adhering to guidelines, impaired reporting and cohort analysis and diminished capacity of the workforce are all described as impacting negatively on treatment outcomes.

The treatment journey was used as the first step in the situational analysis to identify challenges and implement a quality improvement programme. By focusing on patient-centred care, assigning responsibility and establishing systems, facility-level resolution of many of the problems identified was possible. On-going support and supervision, together with systems for monitoring accountability for individual clinicians, facility and district managers is essential in ensuring patients receive optimal treatment.¹⁷

Conclusion

Although this describes one patient's journey, many others follow a similar path. And whilst some obstacles to sub-optimal treatment need resolution at a national or provincial level, many of the problems occur at a facility level and can be resolved at this level.

Visual representation of the patient's treatment journey was useful in describing the extent and summation of health system obstacles to optimal treatment. Further research needs to consider how the health system performs for each individual patient, and measure the relationship with individual treatment outcomes.

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Figure.
 Treatment journey of patient co-infected with MDR-TB and HIV